Parent identity and family-school partnerships: Animating diverse enactments for (special) education decision-making

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Abstract

Family-school partnerships between family members and school personnel can be successful as well as unproductive for parents who have children and youth with developmental disabilities. This qualitative study sought to capture parents' identities as they negotiated family-school partnerships when making inclusive education decisions and discussing special education service-delivery options for their children and youth with developmental disabilities. Seventeen participants shared their personal narratives in interviews and focus groups. Data were thematically analyzed after an initial round of open-coding generated broad themes. Findings revealed the experiences parents have in partnering with schools span an identity spectrum, including: (a) victim, (b) advocate, (c) perseverer, (d) educator, (e) broker and negotiator, and (f) surrenderer. Implications for policy, practice, and research focus on parent identity and family-school partnerships.

Keywords: parent identity, parent agency, inclusive education, family-school partnerships

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Family-school partnerships are defined as the ways in which family members (not just parents) and schools engage in reciprocal and intentional decision-making for the student's benefit as well as family's and school's indirect advantage (Bryan & Henry, 2012; A. Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015). Such partnerships are critical throughout a child's education. For example, family-school partnerships benefit students by positively impacting their attendance (Epstein & Sheldon, 2002) and academic achievement (Toldson & Lemmons, 2013). Reciprocal family-school partnerships also influence the connections families make with one another outside the school when schools embrace each family's unique assets and foster community connection and resource sharing (Hill & Taylor, 2004). Additionally, family-school partnerships support schools' development and maintenance of high-quality inclusive educational experiences for all students (Haines, Gross, Blue-Banning, Francis, & Turnbull, 2015). In sum, family-school partnerships for education decision-making provide central benefits to students, families, and schools throughout the schooling years.

Despite the positive effects of family-school partnerships, such teaming can be especially difficult to cultivate and maintain for families with children and youth with disabilities (Harry, 2008; Blackwell & Rossetti, 2014), particularly children and youth with developmental disabilities (i.e., autism, intellectual disability; Fish, 2006; Ruppar & Gaffney, 2011) protected under Part B of Individuals with Disabilities Education Improvement Act (IDEA, 2004). For example, parents of students with autism have expressed how they are not asked enough for their input on their child's Individualized Education Programs (IEPs) nor do school personnel communicate amply about their child's progress (White, 2014). Moreover, when parents cannot

access IEPs and procedural safeguard packets because of document readability, then parents' opportunities to be informed team members are further compromised (Mandic, Rudd, Hehir, & Acevedo-Garcia, 2012). In addition, parents have described how they are treated contrarily and not as equitable partners by school personnel because their home language is a language other than English (Salas, 2004). Parents from marginalized backgrounds, in particular, have reported how school staff consider them difficult to work with and therefore dismiss their ideas (Lalvani & Hale, 2015). Parents have also been accused of being in denial about their children's abilities and needs because of disagreements with school personnel about educational placements (Harry, 2011; Lalvani, 2014). In conclusion, families of children and youth with developmental disabilities often feel school personnel are reluctant to regard parents as equal partners when making educational decisions (Wagner, Newman, Cameto, Javitz, & Valdes, 2012).

Parent identity is reflective of the ways in which parents interpret exchanges and consequently interact with school personnel while navigating family-school partnerships and decision-making processes (Lalvani & Hale, 2015). The varied ways in which schools partner or fail to partner with families undoubtedly influence parents' perspectives of their roles and identities as team members (Trainor, 2010a). However, the identities parents take on when partnering with school personnel and navigating educational decision-making processes may differ and are not well-documented beyond the broadly conceptualized roles of advocate (e.g., Mueller & Buckley, 2014) and victim (e.g., DeFur, Todd-Allen, & Getzel, 2001). The purpose of this paper, then, is to examine how parents navigate education decision-making processes for inclusive education and special education service-delivery options, subsequently adopt dynamic identities, and enact various values while partnering with school personnel. Two empirical questions guided this study:

1. What identities do parents form when interacting with school personnel to make inclusive education decisions and discuss special education service-delivery options?
2. How do parents reflect and enact their values through varied roles and identities within family-school partnerships?

Consequently, we begin this paper by describing the existing literature focused on parent identity as parents who have children with developmental disabilities make educational decisions within family-school partnerships. Then, we introduce our conceptual framing grounded in Holland and colleagues' (1998) conceptualization of identity. Finally, we recognize identities parents adopted while working with educational teams. Exploring parents' experiences in these ways may provide a deeper understanding of how school personnel include or exclude parents from family-school partnerships and the types of supports required for true partnership, depending upon the identities and roles parents adopt.

Literature Review

Current research has exposed some of the ways parent identity is influenced by parental experiences when making educational decisions for their children and youth with developmental disabilities. Next, we review the extant literature. Then, we discuss our conceptual framing.

As discussed, familial experiences partnering with school personnel can impact parent identity (Lalvani & Hale, 2015). These understandings can change the way parents view their role in the decision-making process from the ideal of being an equal participant to that of a defender. Previous studies have examined how parents of children and youth with developmental disabilities enact advocate identities in unique ways (Carter, Swedeen, Walter, & Moss, 2012; Hess, Molina, & Kozleski, 2006; Lalvani, 2013; Mueller & Buckley, 2014; Trainor, 2010a, 2010b). Scholars have also revealed how partnering with schools to make education-related

decisions has resulted in parent victimhood (DeFur et al., 2001; Harry, Klingner, & Hart, 2005). The ways in which parents advocate for their children and youth with developmental disabilities or the ways in which they are victimized vary widely. For example, Harry and colleagues (2005) found that school staff treated parents disrespectfully, talked to them sarcastically, and ignored their input during meetings. That said, parents' experiences as advocates and/or victims may also influence other identities they adopt when partnering with schools.

Power Imbalances Impact Parent Identity

Scholars have found that parent advocacy is purposeful, temporal, and met with power inequities. Some parents begin advocating when they notice their child is struggling at school (Harry et al., 2005; Hess et al., 2006). While advocating, parents have described the power imbalance between themselves and school personnel (Harry et al., 2005; Hess et al., 2006; Mueller & Buckley, 2014). Parents have also discussed how they fought to be heard (Mueller & Buckley, 2014) and to be considered an expert by school personnel when discussing their child's life (DeFur et al., 2001; Harry et al., 2005; Trainor, 2010a). Other times, parent advocacy began when school personnel brought a struggle a child was having to their parent's attention (Harry et al., 2005; Hess et al., 2006). Thus, power imbalances negatively influence parents' identities as experts of their children's needs. Such imbalances can be victimizing and position parents as defenders of their children and themselves (Harry et al., 2005). Irrespective of when, how, or why advocacy began, parents have shared the nuances of imbalanced power-sharing with school personnel when advocating for their children and youth over time.

Capital and Privilege Impact Parent Identity

Scholars have also found that advocacy is impacted by capital and privilege. For example, Trainor (2010a, 2010b) discussed how parents who had access to resources and

pathways to information related to special education decision-making and IEP processes (cultural capital) were afforded more power and more often valued for their advocacy efforts than parents who did not have this capital. Relationships with people (social capital) have also proven fruitful for families advocating for services and supports and even more so when a parent's social capital was paired with existing cultural capital (Harry et al., 2005; Trainor, 2010a, 2010b). Carter and colleagues (2012) examined parent advocacy within parent-led community conversation events (social capital). Here, families leveraged the events as unique avenues to apply their advocacy skills broadly (cultural capital) as "allies and solution seekers" (Carter et al., 2012, p. 20). In fact, some parents have the social capital to partner with other parents and concerned community members to advocate for inclusive education (Carter et al., 2012), special education service delivery (Trainor, 2010a), or learn about special education processes (Hess et al., 2006; Trainor, 2010b). Thus, whether parents are able to enact the advocacy identity is influenced by their access to social and cultural capital. Forms of capital and privilege impact parent identity while making educational decisions.

Institutional Attitudes Impact Parent Identity

Parents have also argued how their own sense of advocacy has been compromised when school personnel impose their attitudes and perspectives on them in ways that impacted their children's educational needs and victimized the parents (DeFur et al., 2001; Hess et al., 2006; Lalvani, 2013). For example, Lalvani (2013) discussed the impact of institutional resistance on mothers' advocate identities when negotiating or securing inclusive education placements for their young children. In that study, school personnel countered the mothers' requests by identifying self-contained classrooms as the appropriate placement when transitioning from preschool (Lalvani, 2013). When making educational decisions, including post-secondary

transition planning, parents have also cited professional biases as barriers to partnership wherein parents have felt isolated and excluded from the school team (DeFur et al., 2001; Harry et al., 2005; Hess et al., 2006). Moreover, parents have discussed being treated differently based on their race or ethnicity (Angelov & Anderson, 2013; Montgomery & Singer, 2017). In conclusion, institutional attitudes and perceptions impact parents' experiences and identities when partnering with school teams to make educational decisions.

In sum, the extant literature has illustrated select identities parents enact while making educational decisions for their children, including those of advocate and victim. The present study adds to this literature by expanding on the potential identities parents may enact within family-professional partnerships during educational decision-making for their children receiving special education services. Next, we describe our conceptual framing for this analysis.

Conceptual Framing

The present study investigated parent identity as parents partnered with school professionals for inclusive education decision-making and discussed special education service-delivery options for their children. This analysis focused on how parents' identities were both influenced by and illustrative of their actions. We used A. Turnbull and colleagues' (2015) definition of *parent* as anyone who takes on a primary caregiving role, carrying out the functions that a family member would typically perform. Grounded in what it means to be a parent, we used Holland and colleagues' (1998) conceptualization of *identity* as a dynamic, social-construction shifting over time through constant transformation.

As Holland and colleagues (1998) articulated, personal life histories and cultural patterns and practices shape identities. Social interactions and relationships inform identities and reflect varying levels of power and positioning mediated by discourse, access to resources and

materials, and spatial geographies. For parents, the social interactions and relationships developed and maintained through family-school partnerships may influence parent identity. Consequently, parent identity is also impacted by parents' experiences making educational decisions with school personnel for their children and youth.

We defined educational decision-making broadly to ensure consideration of the countless resolutions parents and schools make concerning a child's education. While educational placement (e.g., general education classroom, special education classroom) is commonly considered, other factors are also critical. Such factors include related services, accommodations and modifications, supplementary aids and services (in inclusive settings), and goal-setting and progress monitoring (Wakelin, 2008). Therefore, parent identity is influenced by interactions and relationships as well as the decision-making experiences parents have with school personnel.

The literature on parent identity and decision-making to date reveals some of the roles parents enact when partnering with schools to make decisions. However, there is a dearth of literature examining the myriad identities parents adopt when navigating decision-making processes for inclusive education and service-delivery options as well as how parents enact their values through school partnerships. Consequently, this study sought to examine how parents navigated education decision-making processes for inclusive education and special education service-delivery options and adopted dynamic identities and roles while partnering with schools.

Method

This analysis drew from data collected as part of an interview study (Author et al., 2017) that more broadly focused on the experiences parents of children and youth with developmental disabilities have partnering with schools during education decision-making processes.

Participants and Settings

The research team recruited parents of children with developmental disabilities to participate in interviews and focus groups through emails and flyers and through professional contacts in a snowballing method (Merriam, 2002). Specifically, the principal investigator emailed informational flyers and letters describing the purpose of the study to family support groups in two Midwestern states, including Autism Society of America, Down Syndrome Guild, and Down Syndrome Society. The team solicited participation from parents via the abovementioned support groups because we were interested in hearing from parents of children with autism spectrum disorder and/or intellectual disability. Parents who received the emails were asked to invite other parents of children with developmental disabilities to focus groups, in line with a snowball recruitment method. Due to these indirect recruitment methods, the number of potential participants contacted is unknown. Ultimately, seventeen parents participated, including 15 biological mothers, one biological father, and one foster mother of at least one child with a developmental disability (i.e., autism spectrum disorder, intellectual disability). Please see Table 1. In one instance, two parents represented one family – one biological mother and one biological father (included in the participant total above). The families lived in two Midwestern states in rural, suburban, and urban areas. Their children were 6-20 years old and were receiving special education services.

Role of the Researcher

The research team was made up of one faculty member and three doctoral students. All team members were female, and one identified as a woman of color. None of the members were parents, however some had siblings or relatives with disabilities. All the team members had been teachers prior to working on or completing their doctoral studies in special education. The

research team shared common scholarly agendas focused on inclusive education and family-school partnerships. Based on the literature, personal teaching experiences, and research interests, the team hypothesized that parents may be having mixed experiences advocating for inclusive education and making special education-related decisions for their children with developmental disabilities. We sought to better understand the experiences parents were having with school teams relevant to their children and youth with developmental disabilities.

Data Collection

Interviews and focus groups took place over the phone and in-person and were conducted by members of the research team facilitating the discussions. At least two (and never more than three) research team members were present during every interview and focus group. We obtained informed consent from each participant prior to the start of the interview. An interview protocol guided the discussion with question topics focused on decision-making, special education, and inclusive education. The same protocol was used regardless of interview or focus group configuration and included prompts such as: Tell us about the process of deciding your child needed special education services. Are there services you would like to have for your child, but are not being provided? Do you think inclusion is right or best for your child – why or why not? What supports are provided to your child in inclusive settings?[1]

Questions and conversations were open-ended and were at times directed by the participants (Merriam, 2002). For example, the questions "What is the first thing that comes to mind when you hear the words *special education*?" and "What do you think of when you hear the words *inclusive education*?" prompted a range of emotions and reactions. Depending on the dyad or triad, the parents would sometimes ask one another questions or speak openly without

[1] A full copy of the interview protocol can be obtained by contacting the lead author.

prompts from the research team. Other times, participants empathized with each other or gave one another advice. Open-ended questioning allowed for responses to reflect intergroup and intragroup differences and the nuances of firsthand experiences (Merriam, 2002). Each interview or focus group lasted approximately two hours. The team scheduled interviews and focus groups solely based on participant availability and location as parents often lived great distances from one another. The team conducted a total of three interviews and six focus groups, meaning three parents participated in interviews while 14 parents participated in focus groups consisting of 2-3 parent participants. The focus groups and interviews were audio recorded and sent to a third-party transcription service.

Data Analysis

The research team met weekly or biweekly throughout data analysis. First, the research team analyzed an initial subset of transcripts using open coding to identify themes inductively. The team used rich description in the form of participants' quotes (Saldaña, 2009) and constant comparative analysis to uncover emerging themes and categories (Merriam, 2002). Although inductive analysis is like grounded theory, the team focused on data analysis as it related to the research questions regarding the identities parents formed and how they reflected their values through roles and identities (Maxwell, 2013; Merriam, 2002). *Advocate*, *Educator*, and *Victim* were the first organizational categories defined. *Broker and Negotiator*, *Surrenderer*, and *Perseverer* emerged as substantive categories (Maxwell, 2013). Therefore, preliminary analysis resulted in six major code categories.

Then, the first author reread all the transcripts and used axial coding to place categories in relationship to one another. Axial coding allowed the author to compare, reorganized, and modify (e.g., collapse, expand) categories. During this round of coding, the primary code

category of *Broker and Negotiator* was divided into the sub-codes of *Facilitate partnerships* and *Plan for future services.* Afterwards, the first author designed a codebook with the refined categories grounded in the two research questions (Rodwell, 1998). The codebook was a living matrix containing code definitions, quotes from participants, and non-examples to guide the first and second authors through the transcripts (Maxwell, 2013).

Then, for intercoder agreement, the second author coded excerpts from the transcripts using the codebook. The second author completed a code training test with Dedoose (2018) and received a kappa score of 0.62. Afterwards, the two authors met and refined the codebook, reaching consensus on code discrepancies. With this revised codebook, the second author took a new test and obtained a kappa score of 0.87, indicating excellent agreement. Next, second level intercoder agreement was achieved by applying the codebook to four transcripts, representing two interviews and two focus groups for a total of six participants. The first two authors continued to meet through this iterative process, applying the codebook to the transcripts. During the second level of intercoder agreement, the first two authors met after coding each transcript, reached 100% consensus on discrepancies, and modified the codebook when needed.

Credibility and Trustworthiness

The research team sought credible qualitative inquiry through the following mechanisms. First, the team returned transcripts to the participants for first-level member checking in which parents could elaborate on or delete information (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Respondent validation is critical to ensure that meaning and interpretation are accurate and plausible (Merriam, 2002). We asked each participant to make any corrections, deletions, or additions to their transcription. Five participants responded with edits, corrections, and additions. The team members discussed this and decided to use only the edited transcripts in

the data analysis. Next, we achieved triangulation through data and investigator triangulation as the team used multiple transcripts from interviews and focus groups as well as multiple investigator coders (Brantlinger et al., 2005). Additionally, the team looked for evidence inconsistent with the themes. Being mindful of disconfirming evidence was imperative after establishing the preliminary themes and categories (Brantlinger et al., 2005). Finally, research team members who were present during respective interviews and focus groups engaged in reflexive practices through self-disclosure during debriefing sessions that took place after each interview and focus group. All members engaged in reflexivity while in team meetings throughout data analysis as well (Merriam, 2002).

Findings

The purpose of this study was to examine how parents navigate education decision-making processes for inclusive education and special education service-delivery options, subsequently adopt dynamic identities, and enact various values while partnering with school personnel. Interviews and focus groups revealed that parents adopted particular identities and value enactments when partnering with schools during education decision-making processes. Six themes occurred across interviews and focus groups. In the following sections, we discuss the six themes which emerged as parent identities: (a) victim, (b) advocate, (c) perseverer, (d) educator, (e) broker and negotiator, and (f) surrenderer.

Victim Identity

During interviews and focus groups, parents shared their perspectives of schools failing to collaborate with them (e.g., making decisions without their input) and the sacrifices parents made due to a lack of partnership. We defined the victim identity as parent perspectives focused on traumatic and intimidating experiences that are caused by a school's failure to partner with

families and/or provide services, information, and options. Victimhood resulted from school professionals' failure to partner with families, the experience of trauma-inducing interactions, schools intimidating parents, and parents feeling forced to make sacrifices.

First, parents' perspectives of school professionals' failure to partner with them resulted in parent victimhood. The failure to collaborate took on many forms, including ineffectively teaming with families, excluding parental perspective, and passing judgement. "It's supposed to be a team environment to where everybody can make decisions together, but they take our power away," said one parent. Parents also discussed the prevalence of pre-IEP meetings where school personnel made decisions without parents' attendance. When reflecting on collaboration, one parent stated, "You know you're not part of the IEP team."

Victimization was also expressed as trauma by parents. Parents described traumatic experiences with words such as, "anxiety-provoking," "explosive," "frustrating," "emotionally draining," and "stressful." Parents shared that having a child with a disability in the school system was "jarring," "wreaked havoc" on their life, and put them "through hell." Other traumatic experiences included feeling like they were always wrong or never knowledgeable. "They made me question my sanity. Like, 'How could you ask for this?'" said one parent. "The [school district] here treats me like I'm just dumb as a post," shared another. That said, traumatic experiences left some parents feeling judged, powerless, and burdened by the school.

Parent perceptions of intimidating school or district postures also resulted in victimhood. "Parents are so intimidated to come into an IEP meeting, or any kind of meeting," shared one parent. Parents described the presence of district-level or legal staff at IEP meetings unbeknownst to the parents, contributing to feelings of intimidation. Several parents explained that they no longer had meetings solely with school personnel after past conflicts or parental

requests. Rather, school districts began having an attorney or additional district office personnel (e.g., Director of Special Education Services) present. Parents also discussed feeling bullied. "They get angry at you," explained one parent. "We know [the schools] are going to bully you. [Schools say] 'this is what we're doing with your kid,'" expressed another. Fear of school retaliation because of parent honesty and action in accordance with their rights was also revealed. "We were afraid that if we went to mediation over this last year that there would be retaliation," stated one parent. This fear further contributed to an apprehension to ask for more. In these ways, parents' observations of intimidating postures and processes victimized parents.

Lastly, sacrifice exemplified the victim identity. Sacrifice emerged as a theme when parents discussed forfeiting life elements. Some families physically moved to other towns or districts or gave up their careers (i.e., losing a job, leaving a profession). When parents perceived that their children were not receiving adequate services, they decided to pay for resources and services such as speech and occupational therapy, academic tutors, and assistive technology, with their private funds. One parent discussed modifying classwork so that her daughter could be successful in the general education setting because it was an agreed-upon, but absent, accommodation. The school's failure to provide services that parents viewed as important forced parents to make sacrifices that often affected the entire family.

Advocate Identity

The parent advocate identity presented as an enduring battle on behalf of their own child and other children. We defined advocate as, parent perspectives focused on advocating or battling for their own child and others (children and families) as well as serving others. Through the advocate identity, parents enacted their beliefs and values regarding their child's necessary skills, life outcomes, and educational rights. Many parents described the act of advocacy as a

form of resistance, using such words as “battling” and “fighting.” When discussing her voluntary attendance at school board meetings one parent exclaimed, “I am going to stand up and I’m going to fight for my kid.” Another parent spoke about mending her battle scars because she had “been at war for 16 years” with a district. Other times, advocacy meant preparing for possible confrontation. One parent described going to IEP meetings with her “guns loaded” to contest deficit-laden views educators used to describe her daughter. The resistance parents embodied through their advocacy was deeply personal and often perceived as a battle that waged for years.

Some parents advocated for their child or youth with legal action. Legal action included due process hearings and discrimination or civil rights complaints. One parent described filing a discrimination complaint with the school district and the U.S. Department of Education Office of Civil Rights, because she felt it would result in more sustainable solutions. Visibly inequitable treatment in school-wide publications and physical abuse from school personnel were catalysts for parents’ legal action. Taking legal action was a way parents enacted their value of non-discriminatory educational practices for their children. While parents described their experience of other identities as largely a matter of how school professionals treated them (and their responses to such), the advocate identity directly related to their desire to have the law fulfilled for their child and other children with developmental disabilities. Their pursuit of legal action reflected their beliefs that school personnel should be held accountable and uphold certain principles and ethics including non-discrimination, equal protection, and opportunities to fulfill individual capabilities.

Parents also enacted their role of advocate by battling on behalf of others and through acts of service. For example, parents described advocating on behalf of teachers and paraprofessionals as well as for inclusive settings, classroom resources, and related services.

They expressed their advocacy communication strategies (e.g., writing, via phone, in person) as "barking" and "rocking the boat." Advocating for more positive language was often discussed with school personnel specifically pertaining to educators' perspectives, language use in IEPs, and the broader school experience. This included frequent reminders about their child's strengths and/or long-term life goals. One parent attended every IEP meeting with a three-ring binder adorned with her daughter's photo and the school's mission statement on the front. She shared, "I did go into our last IEP and they had two sentences of how great she was and then a page and a half of all of her weaknesses. I said, 'I have a problem with this.' I said, 'This is not the only thing that's great about her.' She described how she encouraged the staff to write about the progress her daughter was making, as verbally acknowledged by the school personnel.

One route parents took to advocate for other families and children was by volunteering as parent advocates during IEP meetings. "I have fought for my child and I've fought for other parents and other kids. I just don't think that's what it's supposed to be," said one parent. Another described her position as a volunteer advocate for families, "I've signed up to be a parent, like a come alongside parent, for parents who are floundering and have no idea [how to advocate for their child]." Parents undertook such volunteer positions on top of full-time jobs, advocating for their own children, and caring for their families. These actions within the advocate identity represented parents enacting their beliefs that children with developmental disabilities have a right to certain services and equal membership in their local communities, and that all parents have a right to contribute to educational decision-making. Advocating for other parents also occurred in real-time during the focus groups. For example, one participant told another, "And I'm giving you permission to contact me, so I can be some sort of support person

for you." In this way, advocating for others symbolized a relentless pursuit to resist the turmoil many parents experienced while also impacting the broader community.

Finally, parents advocated for other families by serving on boards and commissions or as parent liaisons. "I actually ran and served on my school board and I think that was the first time they ever got pressed on what are you doing for my kid," explained one parent. Another parent acted as a liaison between a major university and local families as the university sought to connect with families on their experiences with school processes. One parent created a website with information and resources for parents, while another developed a non-profit organization that provided Section 504 and IEP resources. These efforts served to foster information access to and advocacy for fellow families.

Perseverer Identity

Perseverance emerged through parents' narratives. We defined perseverer as, parent perspectives focused on their demonstrations of hope, resourcefulness, and personal growth. Persevering was a unique identity different from advocating over time because while parents shared their challenges and triumphs, it became evident that many were developing a new sense of hope. Along with hope, parents also discussed gaining new skills. Therefore, parents were capitalizing on their resourcefulness and growing personally and professionally because of their experiences partnering with schools and making educational decisions.

Parents demonstrated hope for their situation and one another's. "So, there is a light at the end of the tunnel because I would not have been able to survive another semester like last semester," said one parent. When discussing the uncertainty surrounding post-school outcomes, another parent explained, "You know, take it one day at a time, and see." One parent told another, "This part gets easier. I'm telling you," based on her experiences navigating the

community's deficit perspective of children with Down syndrome. Parents' demonstrations of hope seemed to console or reassure themselves, and other parents when in a focus group, and bolstered their resolve to continue advocating for their children and other children and families.

Parents characterized their resourcefulness by sharing examples of times in which they intentionally acted to become more informed, seek support, and find resources. For example, one parent described, "I feel like I know more, because I studied it. I have a copy of the special education handbook in my office. When we were going through the due process, I could almost quote that chapter." Parents sometimes sought advice and help within the school setting. They attended conferences, connected with families and school personnel outside of the district, and invited experts to visit their child's school. One parent reflected on the process of finding a school willing to provide supports for her son. "The best source for information for me to make that [placement] decision was other parents," she explained. Parents also went to workshops offered by local parent training and information centers.

As parents learned how to navigate educational systems and processes, they developed strategies that cultivated their resourcefulness. One parent shared how she and her husband would sit together the night before an IEP meeting and highlight the IEP, including where they had questions and recommended changes. Another proclaimed "killing them with kindness" as her go-to strategy. Parents talked about communication techniques they had learned through trial and error. One parent commented that she had learned to always attend an IEP meeting with another parent or an advocate because having someone else there made it more likely that school personnel would be collaborative by adding another person who she felt had the best interests of her son in mind. "I never go alone," she said. Other strategies included building relationships

with school personnel to be viewed as a team member. “I want my kid educated, so I want to… [show] them that I am a team player. I’m being part of this team,” expressed one parent.

Parents created, attended, and led parent support groups as part of the resourceful, perseverer identity. Some parents connected through social media. From some parents’ perspectives, these strategies afforded them opportunities to commiserate with others, seek counsel, and make their experience public. Not only were they able to find supports for themselves, but they saw the value and necessity of being there for others. “I need to share what I know,” stated one parent. Thus, by developing these networks, parents enacted a value of community and collective agency.

Parents frequently reflected on how they had personally and professionally grown through their efforts to partner with school personnel for placement and service decisions. One parent explained how she benefited from being out of her comfort zone, “So just being forced to become the level of an advocate he has needed has put me in a very uncomfortable position for me, but it has definitely been a growing experience.” When discussing the reality of having to advocate for an inclusive classroom setting each school year for her now high school-aged daughter, another parent stated, “It’s been great. I mean, [advocating for inclusive classrooms every school year] made me the advocate that I am… because I advocated for her and wanted to be keep her in an inclusive classroom throughout.” In these ways, parents countlessly revealed how their resistance and perseverance were part of their identity and supported their growth.

Educator Identity

Parents are inevitably their children’s life-long teachers. However, the parent identity as an educator extended beyond what is typical for most as parents took greater responsibility for

their child's learning. We defined educator as, parent perspectives focused on teaching their children, other families, and school personnel.

Parents described becoming educators because they were leery of a teacher's preparation, lost trust in the school, or were denied services for their children. One parent resorted to homeschooling for many years. Another mother joked about homeschooling, "I mean I laugh when people talk about homeschooling because I was like, well I send him to school and then he comes home, and we homeschool." It was common for parents to talk about supplementing or reinforcing skills at home that they valued but were not seeing developed at school, including stress management strategies, social and communication skills, and fine motor skills for writing. Parents supplemented the education schools provided when they did not agree with the perceived level or type of service provisions.

Parents extended their educator identity to other parents by being accessible to talk about their strategies when others had questions about IEP meetings and supplemental home instruction. One parent expressed, "I make myself available to talk to other parents and I tell them this is what I've done to get to where we are." Others discussed how they provided fellow parents they had met along the way with tips and resources (e.g., who to contact in the district for specific concerns, what private, local speech/language pathologist was their favorite). Akin to their advocate role, the parent educator identity was constant and far-reaching to other families.

Parents also educated school and district personnel as one mother stated, "[parents must] educate the educators." Another added, "Teaching the teachers how to work with [my daughter]" was a reoccurring task. Some parents offered school personnel websites and other resources. One parent proposed trainings specific to her child's needs and subsequently successfully taught the school personnel about food allergies. Whether their knowledge and skills were embraced or not,

parents educated school personnel about their children's strengths and needs, and resources that could help them better support children with developmental disabilities.

Broker and Negotiator Identity

Parents facilitated family-school partnerships and planned for their children and youth's future services as brokers and negotiators. We defined broker and negotiator as, parent perspectives concerning planning for current and future services as well as facilitating family-school partnerships. Some parents developed and maintained family-school communication and partnership by serving as members of parent-teacher organizations. One parent shared, "I participated in fundraising and volunteered in all kinds of ways to make it worthwhile for them to take care of my son." Parents strategically volunteered to obtain more services for their children and to convince school personnel to see them as a part of the school team. Similarly, another parent explicitly described this strategy, saying "You will get more services if they see you in the school." Finally, another parent concurred, "I volunteer in the classroom, I help bake cookies, I do whatever [they need], because they will go above and beyond for my kid if I make their life easier." From the parent perspective, volunteering was one way to barter services.

Other family-school partnership techniques included parents giving educators notes or implementing actions of gratitude. "I thank them every single time I talk to them. Like every note I send, 'Oh thanks for all you do.'" Parents communicated with teachers through email, text, journals, and even post-it notes. "I send sticky notes on her agenda to the school, and I'm always like thank you," explained one mother. While parents were genuinely grateful for positive relationships with teachers and respected their work, these acts of gratitude existed with the specific purpose of maintaining communication with school personnel and increasing the chance of positive experiences for their child. When these strategies worked, parents described positive

relationships with teachers. For example, one mom shared that she talked daily with the teachers, got immediate responses over text, and had a "great relationship" with them. In addition to thank you notes, parents mentioned taking food to the staff to show appreciation. Showing gratitude to school personnel was another bartering technique as broker and negotiator.

In addition to facilitating their current partnership with the school, parents spent extra time planning for the next year or subsequent years to prompt educators to think about future needs or children's long-term outcomes. When reflecting on the route her family took to find the appropriate school for their son, one mother shared, "It worked out really well, but it took a lot of planning. It took money. It took a lot of thought." This mom talked extensively with school personnel and service providers from multiple schools, and while she was happy with the outcome, she acknowledged her planning, privilege, and available resources as integral to the positive outcome. Moreover, future placement decisions were a particular topic that parents frequently planned around. One parent had been able to get her daughter into an inclusive general education setting for second-grade, but immediately began worrying about her daughter's future third-grade teacher. Parents viewed such future planning as necessary for them to strategically determine what they would need to do (or who they would need to talk to) to get the placement and services they desired for their children. Parents also shared examples of independently planning for the transition from middle to high school as well as post-school options. One parent had already decided she would start a non-profit organization to employ her (currently middle-school aged) son and other young adults with developmental disabilities. She discussed thinking about what she would personally need to do to ensure her son had something to do after graduating high school. Planning for future services was a constant thought. It could include next day planning or preparing for months or years ahead.

Surrenderer Identity

At times, parent identity and action were influenced by the degree to which parents surrendered their identities as negotiators, advocates, and educators. The sixth theme, surrenderer, speaks to this dynamic and fluid process wherein parents moved in and out of a state of yielding. We defined surrenderer as, parent perspectives that reveal settling with or yielding to school and district personnel's' decisions regarding educational placements and services. Surrendering appeared when parents were content with service delivery or when they had relinquished the struggle and, from their perspective, settled for less than ideal placements or services. Holding this identity, parents found contentment in a range of services and within both inclusive classrooms and segregated placements.

When surrendering took on the appearance of service contentment, parents described their satisfaction with the team as "great" or "really special." For example, one parent who was content with their child's services described the school setting as "optimal" while another parent shared, "I love the program my kid is in now." Content parents were often not only satisfied with a teacher or service provider, but also expressed agreement with the entire school team or setting. Parent contentment was typically the result of a staff member's responsiveness or when parents felt as though the school was meeting their child's needs. One parent also expressed that her child was making "so much progress." As expressed by this quote, parents were assessing the effectiveness of services and their child's needs based on progress and outcomes; they were not choosing what they wanted for their child without evidence.

Unfortunately, surrendering was sometimes the result of advocacy fatigue. That is, some parents described abandoning the fight for certain services or placements because of exhaustion from previous disagreements or the schools' continued ambivalence towards their participation

in decision-making. One mother explained, “I mean, there have been times that I’ve walked in and I just don’t have it in me. I don’t let them take anything away from her, but I don’t have it in me to fight for more.” Responses like this indicated parents’ perspectives on the compounded effects of continually advocating or fighting for services for their child. Others abandoned the struggle to maintain relationships with school personnel. One parent expressed that she did not “always want to be that [fighting] mom.” Such parents described having to choose their battles and relinquish their preferences so that they would be perceived as someone the school could work with, thus avoiding a reputation that might negatively affect them in the future.

Surrendering also occurred when parents settled for less than what they had originally wanted. In one instance, a parent described satisfaction with obtaining desired therapies even though it came at the expense of their child being placed in a segregated classroom. “The plus side is he is getting therapy all day long and I love that,” she said. She discussed how her family filled the social gap created by a lack of peer interactions with, “Scouts and… swim lessons, and you know doing other things that are more typical kind of activities.” In this instance, the mother surrendered to receive one of the two things she wanted – therapy for her son. For another mother, it was more important that her daughter be in a segregated setting, regardless of how it perpetuated her daughter being “invisible” because she felt the school could not provide effective instruction in the general education classroom. Multiple parents described this challenge of choosing whether to fight for placement or services and needing to surrender to a less-than-desirable decision. Regarding inclusive placements, this often meant that parents were prioritizing either their beliefs about inclusive education or their value for appropriate services.

Finally, surrendering was sometimes the result of schools treating parents as members of the decision-making team, even if they did not get everything they had originally wanted. One

mother expressed this contested satisfaction with her district, saying, “I mean, they are just very welcoming, and you know it’s not 100% and there [are] still things that need to be worked on, but it’s just head and shoulders above other districts that I’ve seen.” As parents surrendered, they found positive and hopeful perspectives within challenging situations, thus adding to the nuanced experience of the surrenderer identity.

Overlapping Identities

Finally, it is important to note that parent identities were not mutually exclusive. For example, when parents’ experiences with school personnel were victimizing then parents sought out solutions that resulted in enacting an educator identity. One mother explained, “I’m paying a car payment every month to teach my son how to read and that’s what I’ve got to do.” Parents discussed how a lack of options or school personnel’s failure to partner with them led them to take up educator identities to teach their children critical skills. The victim identity also overlapped with the persevered identity. Other examples of coinciding identities emerged between as perseverers and educator. In sum, parent identities often intersected and overlapped as parents made educational decisions and navigated family-school partnerships.

Our findings illustrate the ways in which parents enact particular identities when making inclusive education decisions and discussing special education service delivery options within family-school partnerships for their children and youth with developmental disabilities. Parents found ways to move in, out, and between identities depending on purpose, significance of the situation, and their energy levels. The parents in this study explained how school personnel failed to collaborate with them and view them as equal partners. Instead, parents described the ways in which school personnel positioned them as adversaries rather than advocates. Parents explained the ways in which they persevered within these challenging circumstances, developed new skills

and capitalized on their budding resourcefulness. Inequitable family-school partnerships also led parents to absorb an expansive educator identity wherein parents were educators not only for their children, but also other families, school personnel, and community members. Parents also explained how they negotiated and brokered for current supports and services for their children as well as for future supports and services. As they considered each circumstance and what lie ahead, parents also surrendered with a range of thoughts and feelings including contentment, fatigue, and dissatisfaction.

Discussion

Family-school partnerships are foundational to IDEA (2004), yet school and district personnel involve parents in disparate ways (Burke, 2017; Elbaum, Blatz, & Rodriguez, 2016; Leyser & Kirk, 2011). The findings of this study reveal important evidence about parents' experiences working with school teams to make inclusive educational decisions and consider special education service delivery options. This analysis sheds light on parental identities and value enactments not currently expressed in the literature and why parents might engage in them. In addition to victim and advocate identities found in previous research (Carter et al., 2012; DeFur et al., 2001; Harry et al., 2005; Hess et al., 2006; Lalvani, 2013; Mueller & Buckley, 2014; Trainor, 2010a, 2010b), four identities emerged from the data in the current study: perseverer, educator, broker and negotiator, and surrenderer.

While the victim and advocate identities have been found in previous studies, the present study added to an understanding of how these identities came to be and the diversity in their enactment. In the present study, the victim identity often resulted from parents' experiences with school personnel who had failed to partner with them as well as from trauma or intimidation caused by the school or district staff. Like previous studies (DeFur et al., 2001; Harry et al.,

2005; Mueller & Buckley, 2014; Trainor, 2010a), parents in this study emphasized the need to remind educators about their child's strengths and convince school personnel to see their input as valuable. As advocates, parents engaged in varied deeds of service to others, analogous to what Trainor (2010b) called The Change Agent. Moreover, acts of advocacy varied wherein parents sought legal action for their children and youth, served as liaisons between families and institutions, and developed informative materials to share with others. Thus, the present study illustrates how parents enacted the advocate identity, in particular, as a way to resist schools' denigration of families. That said, the present study expands our understanding of the advocate and victim identities by exposing how diverse and wide-ranging they can be for parents.

Through parents' stories, the parent identity of perseverer emerged as parents showed determination to learn and contribute to educational decision-making over time. Similar to Bayat's (2007) findings on family resilience, the perseverer identity was characterized by resourcefulness wherein parents of children and youth with developmental disabilities pooled existing resources and felt more connected. The perseverer identity expands on previous findings that parents often seek out resources to instigate better collaboration with schools, particularly when there is conflict (e.g., Bayat, 2007; Tucker & Schwartz, 2013). In the present study, parents cultivated strategies and supports in preparation for IEP meetings in the short term, like other studies identified, but they were also often engaging in long-term planning. Parents displayed remarkable foresight as they seemed to gather resources and develop relationships with the expectation that they would always need such supports. However, the parents in this study also enacted the perseverer identity when demonstrating hope for their future situations and one another's. This study expands on previous findings as parents described how conflict, at times, also led to personal growth and skill development.

The educator identity has also not been thoroughly explored within the family-school partnerships and educational decision-making literature. That is, research has seldom explored how parents take up a teaching role in their child's life. In Boehm and Carter's (2016) systematic review of parents informal relationships, the authors examined how parents of children with developmental disabilities support one another. The researchers found that parents provided other parents with emotional and social support most often. Within this review, only two studies examined the educational or informational supports parents provide (Marcenko & Meyers, 1991; Ow, Tan, & Goh, 2004). In the present study, the educator identity proved to be an important, distinct role as parents discussed educating other families about their rights and beneficial strategies and educating teachers about their children's strengths and needs.

In this study, parents' broker and negotiator identities appeared as they developed and maintained partnerships with schools through their supplementary actions. Similar to Stoner and colleagues' (2005) findings, the parents in this study had difficulty obtaining services and securing high-quality inclusive placements. This led to negotiating and brokering for services. In previous scholarship, negotiation has stemmed from parents' distrust of school professionals (Stoner et al., 2005). This study expands on Stoner and colleagues' (2005) findings as parents expressed other ways they negotiated and brokered for services beyond the IEP meeting and due to myriad reasons. Negotiation strategies, such as using certain communication techniques, and brokering strategies, such as volunteering at school, were utilized not just because parents distrusted professionals, but because parents felt pressured to contribute to their child's classroom and school in exchange for their child's unique needs being met.

Lastly, the surrenderer emerged as a unique identity that has not previously been explicitly identified. Some parents surrendered and settled for less than what they had hoped for.

McCloskey (2010) discussed similar findings unfolding from one mother's experiences. The focal participant acquiesced when she wanted her son to maintain his current therapy services but was denied her request because he would be changing school districts and therefore, receiving services from therapists at his new school (McCloskey, 2010). Similar to those findings, surrendering was not necessarily the result of a lack of advocacy. Instead, parents often felt forced to surrender after advocacy efforts. Parents enacted surrendering with satisfaction when they partnered with a responsive teacher or when they felt the school was meeting their child's needs. Alternately, they sometimes surrendered after fatigue from extensive previous advocacy. In this study, the surrenderer identity spoke to the complexities of yielding with satisfaction or dissatisfaction as parents sometimes made difficult decisions about what they felt was most important for their child.

Implications for Policy

Like previous scholarship (DeFur et al., 2001; Harry et al., 2005; Lalvani, 2013; Mueller & Buckley, 2014; Trainor, 2010a), parents in this study felt otherwise shut-out from decision-making processes and unheard. Parents' experiences in this study as advocates, perseverers, brokers and negotiators, and surrenderers support R. Turnbull's (2005) argument that IDEA (2004) necessitates a significant amount of parent responsibility and privilege. In fact, IDEA (2004) requires so much from the parents in this study that they openly talked about how decision-making processes within family-school partnerships caused them to feel anxious or tired, and spurred them to try to improve the system for both themselves and others.

IDEA (2004) places the onus and burden of monitoring the schools' supports and services implementation on parents. Thus, the law appears to sometimes inadvertently require parents to expend what most families do not have in excess - time, money, capital, and privilege

(Lalvani & Hale, 2015; McCloskey, 2010) - to access the rights already afforded to them through federal legislation. Policy makers at state and federal levels should carefully examine how the educational system forces parents to fight for their afforded rights as well as for their youth's rights (R. Turnbull, 2005).

In order to better address parents' perspectives, future state and federal policy reauthorizations should solicit more family input through a supports model perspective (Kyzar, Turnbull, Summers, & Aya, 2012). A supports model perspective considers emotional, physical, material/instrumental, and informational supports. Such a perspective would allow policy makers to identify the gaps in the supports as well as the sources of support families receive from schools. These are gaps that have resulted in inequitable family-school partnerships and forced parents to adopt a myriad of identities. Conversely, the sources of support would provide access to equitable and reciprocal family-school partnerships. A supports-based framework (Kyzar et al., 2012) in future policy analysis would address parents' diverse identity enactments and could influence policy change focused on fostering successful family-school partnerships for inclusive education and special education service delivery.

Implications for Practice

Quality family-school partnerships are trusting, reciprocal, and value parent input (Francis et al., 2016; Haines et al., 2017). Further, equitable and intentional family-school partnerships provide opportunities for cooperation, creativity, and choice in decision-making processes (Haines et al., 2015). These are critical factors schools must consider when partnering with parents because family-school partnerships have countless positive impacts on students' schooling experiences (Epstein, 2018). However, the present study illustrates that these qualities are often missing from family-professional interactions. The parent identities expressed in this

study revealed specific implications for practice because they denote how parents interacted with school professionals, contributed to the educational system, and were or were not able to address collaboration challenges. Considering these parent identities point to specific ways school personnel can improve family-professional partnerships.

First, parents in the present study discussed taking an active role in educating other parents because they felt this was not being done by the schools. Indeed, school and district personnel play a key role in facilitating parent comfort and empowerment (Cook, Hayden, Bryan, & Belford, 2016). For example, school districts can support parents by providing trainings on what parents need information about. Such topics have included special education law and service delivery, communicating with the IEP team, and community-based resources (Aceves, 2014). The trainings and workshops the school or district provide can be organized in partnership with community-based parent agencies and information networks (Montgomery & Singer, 2017). That said, schools and districts play a vital role in facilitating parent empowerment through training and educational opportunities.

Second, study participants reported countless examples of teaching their children. However, schools continued to push against parents' requests for more help as well as parents' demonstrations of expertise. Instead, schools should recognize that parents are taking an active role in educating their children. As schools embrace this perspective shift, they would support parents by sharing child-specific resources and knowledge and be open to what the parent has to offer (Francis et al., 2016; Stoner et al., 2005). In conclusion, to share and cultivate knowledge and resources bidirectionally, school personnel must make shifts in their values and perspectives of parents as educators and equitable partners (Haines et al., 2017).

Finally, the parents in this study discussed their frustrations and exhaustion when trying to work with school personnel. While previous scholarship has examined parent fatigue associated with parenting a child with a disability (Green, 2007; Lalvani, 2015; Myers, 2009), this study illuminates how partnering with schools can also be vexing and tiring. These feelings are especially true when parents are consistently fighting for services and feeling undervalued or disrespected. Therefore, schools should remain cognizant that parent participation in educational decision-making can be exhausting on top of parents' other responsibilities. School professionals could lessen such feelings of frustration and fatigue by connecting families to parent support groups (Lunsky et al., 2017; Jackson, Steward, Roper, & Muruthi, 2018; Spann, Kohler, & Soenksen, 2003). In addition, school personnel can connect with community resource centers to leverage their expertise and to facilitate family-professional partnerships (Montgomery & Singer, 2017). Moreover, research shows that when school personnel restructure IEP meeting norms and procedures based on the five themes of facilitated IEP (FIEP) meetings, they proactively avoid conflict and reduce parents' burdens without taking away parent voice and opportunities for action (Mueller & Vick, 2018).

Limitations and Implications for Future Research

It is important to consider the limitations of this study. The first limitation centers around recruitment. Participants in the present study were recruited from parent support groups for parents of children and youth with developmental disabilities. It is possible that parents who are members of such support groups may have different experiences or resources compared to those who are not members (Spann et al., 2003). Therefore, relying on parent support groups for recruitment is a limitation. Future research should recruit families through a variety of mediums.

Second, while the research team tried to make participation accessible to parents through multiple modes of communication and meeting locations, the experiences of parents representing diverse racial, ethnic, and linguistic backgrounds is missing. Most participants were white biological mothers. Therefore, it is important to acknowledge that parents who are not the dominant group represented in this study (e.g., white, suburban, middle to upper class) may face additional struggles finding equitable, trusting school partnerships (Artiles, 2014; Jegatheesan, 2009) and advocating for inclusive education for their children (Lalvani & Hale, 2015). Therefore, the challenges described by primarily white biological mothers may be even more complex and significant for parents from non-dominant groups. Future research should continue to examine the identities and experiences of fathers as well as parents from culturally and linguistically diverse backgrounds, non-dominant family configurations, and varied socioeconomic statuses to capture the nuanced experiences in education decision-making for their children and youth with developmental disabilities.

Third, this project examined educational decisions made within a team context. However, we did not include the perspectives of other team members. This is another limitation of the current study. As Elbaum and colleagues (2016) recently discussed, another path for future research is to examine the perspectives and roles of educators and school leaders. We would conclude future research should consider the identities and roles of school personnel, other family members, and pertinent community resources when making educational decisions within family-school partnerships.

Fourth, participants may have also responded differently dependent on interview or focus group structure. As discussed, participants often responded to each other and served as a source of support for one another. While a strength of focus groups can be collective remembering

(Huber, 2009), the focus group structure did not guarantee an opportunity for each parent to equally examine individual experiences. Therefore, future research should dive deeper into enacted identities with parents and other caregivers involved in education decision-making through interviews.

Finally, the team did not collect all potentially relevant demographic information. Parent educational background and socioeconomic status remains unknown. Child race or ethnicity was not formally known across participants. Moreover, the team did not verify disability label or classification through a review of records. In order to determine these unknowns, future research would collect more comprehensive demographic data on parents or the interviewed family member and their children and youth with developmental disabilities. Furthermore, with more complete demographic information, future studies could then examine the differences between the experiences of parents of children and youth with particular disability labels.

Conclusion

From the parent perspective, the challenges of creating and maintaining equitable and trusting family-school partnerships for education decision-making for their children and youth with developmental disabilities are overwhelming. The process is often complex and unclear as parents enact various roles to try to positively impact their children's education and ensure appropriate services. Such experiences can be intimidating and isolating. However, parents want to partner, they fight to have access to collaborative opportunities, and they see school personnel as a resource and collaborator. Upholding parent expertise and honoring the many ways parents partner with school personnel is critical for successful education decision-making. From policy to practice, schools and agencies should embrace parents as critical, invaluable partners.

References

Author et al. (2017). [details removed for peer review]

Aceves, T. C. (2014). Supporting Latino families in special education through community agency-school partnerships. *Multicultural Education, 21*(3-4), 45-50.

Angelov, A. D. S., & Anderson, S. L. (2013). On the outside looking in: An African American family's experience in an individualized education plan meeting. *Mid-Western Educational Researcher, 25*(3), 1-20.

Artiles, A. J. (2014). Beyond responsiveness to identity badges: Future research on culture in disability and implications for Response to Intervention. *Educational Review, 67*, 1-22. doi:10.1080/00131911.2014.934322

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*, 702-714. doi:10.1111/j.1365-2788.2007.00960.x

Blackwell, W. H., & Rossetti, Z. S. (2014). The development of individualized education programs: Where have we been and where should we go now? *SAGE Open, 4*, 1-15. doi:10.1177/2158244014530411

Boehm, T. L., & Carter, E. W. (2016). A systematic review of informal relationships among parents of individuals with intellecual disability or autism. *Research & Practice for Persons with Severe Disabilities, 41,* 173-190. doi:10.1177/1540796916657339

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children, 71*, 195-207. doi:10.1177/001440290507100205

Bryan, J., & Henry, L. (2012). A model for building school-family-community partnerships: Principles and process. *Journal of Counseling & Development, 90*, 408-420. doi:10.1002/j.1556-6676.2012.00052.x

Burke, M. M. (2017). Examining empowerment, family–school partnerships, and advocacy among rural and urban Latino families of children with disabilities. *Rural Special Education Quarterly, 36*, 56-63. doi:10.1177/8756870517707218

Burke, M. M., & Sandman, L. (2015). In the voice of parents: Suggestions for the next IDEA reauthorization. *Research & Practice for Persons with Severe Disabilities, 40*, 71-85. doi:10.1177/1540796915585109

Carter, E., Swedeen, B., Walter, M. C. M., & Moss, C. K. (2012). “I don't have to do this by myself?” Parent-led community conversations to promote inclusion. *Research and Practice for Persons with Severe Disabilities, 37*, 9-23. doi:10.2511/027494812800903184

Cook, A. L, Hayden, L. A, Bryan, J., & Belford, P. (2016). Implementation of a school-family-community partnership model to promote Latina youth development: Reflections on the process and lessons learned. *The International Journal of Research on Service-Learning and Community Engagement, 4*(1), 1-17.

Dedoose Version 8.0.42. (2018). Collaborative web-based application for managing, analyzing, and presenting qualitative and quantitative research data. Los Angeles, CA: SocioCultural Research Consultants, LLC. Retrieved from https://app.dedoose.com/App/?Version=8.0.42

DeFur, S. H., Todd-Allen, M., & Getzel, E. E. (2001). Parent participation in the transition planning process. *Career Development for Exceptional Individuals, 24*, 19-36. doi:10.1177/088572880102400103

Elbaum, B., Blatz, E. T., & Rodriguez, R. J. (2016). Parents' experiences as predictors of state accountability measures of schools' facilitation of parent involvement. *Remedial and Special Education, 37*, 15-27. doi:10.1177/0741932515581494

Epstein, J. L, & Sheldon, S. B. (2002). Present and accounted for: Improving student attendance through family and community involvement. *The Journal of Educational Research, 95*, 308-318.

Epstein, J. L. (2018). *School, family, and community partnerships: Preparing educators and improving schools*. New York, NY: Routledge.

Fish, W. W. (2006). Perceptions of parents of students with autism towards the IEP meeting: A case study of one family support group chapter. *Education, 127*, 56-68.

Francis, G. L., Blue-Banning, M., Turnbull, A. P., Hill, C., Haines, S. J., & Gross, J. M. S. (2016). Culture in inclusive schools: Parental perspectives on trusting family-professional partnerships. *Education and Training in Autism and Developmental Disabilities, 51*, 281-293.

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*, 150-163. doi:10.1016/j.socscimed.2006.08.025

Haines, S. J., Francis, G. L., Mueller, T. G., Chiu, C.-Y., Burke, M. M., Kyzar, K., . . . Turnbull, A. P. (2017). Reconceptualizing family-professional partnerships for inclusive schools: A call to action. *Inclusion, 5*, 234-247. doi:10.1352/2326-6988-5.4.234

Haines, S. J., Gross, J. M. S., Blue-Banning, M., Francis, G. L., & Turnbull, A. P. (2015). Fostering family-school and community-school partnerships in inclusive schools: Using practice as a guide. *Research & Practice for Persons with Severe Disabilities, 40*, 227-239. doi:10.1177/1540796915594141

Harry, B. (2008). Collaboration with culturally and linguistically diverse families: Ideal versus reality. *Exceptional Children, 74*, 372-388. doi:10.1177/001440290807400306

Harry, B. (2011). Reciprocity and humility in wonderland. *Learning Disability Quarterly, 34*, 191-193. doi:10.1177/0731948711417556

Harry, B., Klingner, J., & Hart, J. (2005). African American families under fire: Ethnographic views of family strengths. *Remedial and Special Education, 26*, 101-112. doi:10.1177/07419325050260020501

Hess, R. S., Molina, A., & Kozleski, E. B. (2006). Until somebody hears me: Parental voice and advocacy in special education decision-making. *British Journal of Special Education, 33*, 148-157. doi:10.1111/j.1467-8578.2006.00430.x

Hill, N. E., & Taylor, L. C. (2004). Parental school involvement and children's academic achievement: Pragmatics and issues. *Current Directions in Psychological Science, 13,* 161–164. doi:10.1111/j.0963-7214.2004.00298.x

Holland, D., Lachicotte, W., Skinner, D., & Cain, C. (1998). *Identity and agency in cultural worlds.* Cambridge, MA: Harvard University Press.

Huber, L. P. (2009). Disrupting apartheid of knowledge: Testimonio as methodology in Latina/o critical race research in education. *International Journal of Qualitative Studies in Education, 22*, 639-654. doi:10.1080/09518390903333863

Individuals with Disabilities Education Improvement Act, 20 U.S.C. § 1412, (2004).

Jackson, J. B., Steward, S. R., Roper, S. O., & Muruthi, B. A. (2018). Support group value and design for parents of children with severe or profound intellectual and developmental disabilities. Advance online publication. *Journal of Autism and Developmental Disorders*. doi:10.1007/s10803-018-3665-z.

Jegatheesan, B. (2009). Cross-cultural issues in parent-professional interactions: A qualitative study of perceptions of Asian American mothers of children with developmental disabilities. *Research and Practice for Persons with Severe Disabilities, 34*, 123-136. doi:10.2511/rpsd.34.3-4.123

Kyzar, K., Turnbull, A. P., Summers, J. A., & Aya, V. (2012). The relationship of family support to family outcomes: A synthesis of key findings from research on severe disability. *Research & Practice for Persons with Severe Disabilities, 37,* 31-44. doi:10.2511/027494812800903247

Lalvani, P. (2013). Land of misfit toys: Mothers' perceptions of educational environments for their children with Down syndrome. *International Journal of Inclusive Education, 17*, 435-448. doi:10.1080/13603116.2012.683047

Lalvani, P. (2014). The enforcement of normalcy in schools and the disablement of families: Unpacking master narratives on parental denial. *Disability & Society, 29*, 1221-1233. doi:10.1080/09687599.2014.923748

Lalvani, P. (2015). Disability, stigma and otherness: Perspectives of parents and teachers. *International Journal of Disability, Development and Education, 62*, 379-393. doi:10.1080/1034912X.2015.1029877

Lalvani, P., & Hale, C. (2015). Squeaky wheels, mothers from hell, and CEOs of the IEP: Parents, privilege, and the "fight" for inclusive education. *Understanding & Dismantling Privilege, 5,* 21-41.

Leyser, Y., & Kirk, R. (2011). Parents' perspectives on inclusion and schooling of students with Angelman Syndrome: Suggestions for educators. *International Journal of Special Education, 26*, 79-91.

Lunsky, Y., Hastings, R. P., Weiss, J. A., Palucka, A. M., Hutton, S., & White, K. (2017). Comparative effects of mindfulness and support and information group interventions for parents of adults with autism spectrum disorder and other developmental disabilities. *Journal of Autism and Developmental Disorders, 47*, 1769-1779. doi:10.1007/s10803-017-3099-z

Mandic, C. G., Rudd, R., Hehir, T., & Acevedo-Garcia, D. (2012). Readability of special education procedural safeguards. *The Journal of Special Education, 45*, 195-203. doi:10.1177/0022466910362774

Marcenko, M. O., & Meyers, J. C. (1991). Mothers of children with developmental disabilities: Who shares the burden? *Family Relations, 40,* 186-190. doi:10.2307/585481

Maxwell, J. A. (2013). *Qualitative research design: An interactive approach*. Los Angeles, CA: Sage.

McCloskey, E. (2010). What do I know? Parental positioning in special education. *International Journal of Special Education, 25*(1), 162-170.

Merriam, S. B. (2002). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Josey-Bass.

Montgomery, L. S., & Singer, G. H. S. (2017). Just like family: How a community parent resource center serves culturally and linguistically diverse families and promotes inclusive practices. *Inclusion, 5,* 306-320. doi:10.1352/2326-6988-5.4.306

Mueller, T. G., & Buckley, P. C. (2014). Fathers' experiences with the special education system: The overlooked voice. *Research & Practice for Persons with Severe Disabilities, 39*, 119-135. doi:10.1177/1540796914544548

Mueller, T. G., & Vick, A. M. (2018). Rebuilding the family–professional partnership through facilitated Individualized Education Program meetings: A conflict prevention and resolution practice. Advance online publication. *Journal of Educational and Psychological Consultation*. doi:10.1080/10474412.2018.1470934

Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders, 3*, 670-684. doi:10.1016/j.rasd.2009.01.004

Ow, R., Tan, N. T., & Goh, S. (2004). Diverse perceptions of social support: Asian mothers of children with intellectual disability. *Families in Society: The Journal of Contemporary Social Services, 85,* 214-220. doi:10.1606/1044- 3894.327

Rodwell, M. K. (1998). *Social work constructivist research*. London, England: Routledge.

Ruppar, A. L, & Gaffney, J. S. (2011). Individualized education program team decisions: A preliminary study of conversations, negotiations, and power. *Research and Practice for Persons with Severe Disabilities, 36*, 11-22. doi:10.2511/rpsd.36.1-2.11

Salas, L. (2004). Individualized education plan (IEP) meetings and Mexican American parents: Let's talk about it. *Journal of Latinos and Education, 3,* 181-192. doi:10.1207/s1532771xjle0303_4

Saldaña, J. (2009). *The coding manual for qualitative researchers*. Thousand Oaks, CA: Sage.

Soodak, L. C. (2004). Parents and inclusive schooling: Advocating for and participating in the reform of special education. In S. Danforth & S. D. Taff (Eds.), *Crucial reading in special education* (pp. 260–273). Upper Saddle River, NJ: Pearson Education.

Spann, S. J., Kohler, F. W., & Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities, 18,* 228–237. doi:10.1177/10883576030180040401

Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities, 20*, 39-51. doi:10.1177/10883576050200010401

Toldson, I. A, & Lemmons, B. P. (2013). Social demographics, the school environment, and parenting practices associated with parents' participation in schools and academic success among Black, Hispanic, and White students. *Journal of Human Behavior in the Social Environment, 23*, 237-255. doi:10.1080/10911359.2013.747407

Trainor, A. A. (2010a). Reexamining the promise of parent participation in special education: An analysis of cultural and social capital. *Anthropology & Education Quarterly, 41*, 245-263. doi:10.1111/j.1548-1492.2010.01086.x

Trainor, A. A. (2010b). Diverse approaches to parent advocacy during special education home-school interactions. *Remedial and Special Education, 31,* 34-37. doi:10.1177/0741932508324401

Tucker, V., & Schwartz, I. S. (2013). Parents' perspectives of collaboration with school professionals: Barriers and facilitators to successful partnerships in planning for students with ASD. *School Mental Health, 5,* 3-14. doi:10.1007/s12310-012-9102-0

Turnbull, H. R. (2005). Individuals with Disabilities Education Act reauthorization: Accountability and personal responsibility. *Remedial and Special Education, 26,* 320-326. doi: 10.1177/07419325050260060201

Turnbull, A., Turnbull, R., Erwin, E. J., Soodak, L. C., & Shogren, K. A. (2015). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust* (7th ed.). Boston, MA: Pearson.

Wagner, M., Newman, L., Cameto, R., Javitz, H., & Valdes, K. (2012). A national picture of parent and youth participation in IEP and transition planning meetings. *Journal of Disability Policy Studies, 23*, 140-155. doi:10.1177/1044207311425384

Wakelin, M. M. (2008). Challenging disparities in special education: Moving parents from disempowered team members to ardent advocates. *Northwestern Journal of Law & Social Policy,* 3, 261-288.

White, S. E. (2014). Special education complaints filed by parents of students with autism spectrum disorders in the midwestern United States. *Focus on Autism and Other Developmental Disabilities, 29*, 80-87. doi:10.1177/1088357613478830

Parent			Child			Area
Role	Age	Race	Gender	Age	Disability	
Mother	39	White	Male	14	ASD	Urban
Mother	42	White	Female	19	ASD	Rural
Mother	40	White	Male	9	ASD	Urban
Mother	42	White	Female	11	ASD	Rural
Mother	52	White	Female	20	ID	Suburban
Mother	37	White	Male	8	ASD	Urban
Mother	45	White/Latina	Male	18	ASD	Suburban
Mother	47	White	Male	13	ASD	Urban
Mother	49	White	Male	13	ID	Urban
Father	51	White	Male	13	ID	Urban
Mother	54	Asian	Male	19	ID	Urban
Mother	38	White	Male	10	ASD	Suburban
Foster Mother	47	White	Male	19	ID	Suburban
Mother	42	White	Male	10	ID	Urban
Mother	36	White	Male	6	ID	Urban
Mother	38	White	Female	8	ID	Suburban
Mother	38	White	Male	10	ID	Urban

Table 1: Participant Demographic Information
Note: ASD = autism spectrum disorder; ID = intellectual disability.